

## Attachment 3: ME/CFS: Healthcare Provider Perspective Interview

### INTRODUCTION

#### **Voluntary Consent to Participate in a Dyad Interview Discussing Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS)**

Hello/Good morning/Good afternoon.... I want to welcome you to the conference call for the dyad interview.

My name is Dana Brimmer. I am calling from the Synergy America Inc., a contractor for the Centers for Disease Control and Prevention (CDC). We have two people scheduled for an interview regarding Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS). Is this still a good time to do the interview?

If No – May I reschedule the interview at a time that is convenient for you?

If Yes – Before we begin the interview, I need to review a few details about the study with you.

### PURPOSE

This interview is part of a series of interviews called *ME/CFS: Healthcare Provider Perspective Interview*. CDC ME/CFS program wants to hear from healthcare providers about the ME/CFS diagnosis process, managing ME/CFS patients, patient centered outcomes in office visits, and preferred sources of educational materials. The information will help assess current materials, revising materials, and guide education of healthcare

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professionals.

The Centers for Disease Control and Prevention (CDC) is sponsoring this interview; Synergy America Inc, a company headquartered in Duluth, Georgia is the CDC's contractor to conduct this interview.

You have been asked to participate in this interview because you are a healthcare provider that sees patients. We will be conducting up to 30 telephone interviews with other healthcare providers.

Our interview today will take about 30 minutes.

### CONFIDENTIALITY

CDC will treat data in a secure manner and will not disclose, unless otherwise compelled by law. The interview will be recorded so that we have accurate documentation of your responses. As part of a dyad, we ask that you keep the information discussed today confidential. The recording of your interview will be labeled with a study code, not your name. The recording will be transcribed and your name will not be linked to the responses you provide in the interview. The information you provide during the interview will be used in reports to the government in summary form only; your name will not be included in the report. Synergy American Inc. will continue to keep the recording of your interview in secure storage until five years from this interview (Month Year). At that time, the recording will be destroyed.

### VOLUNTARY PARTICIPATION

Please understand that your participation in this interview is voluntary. You may stop at any time. You do not need to give a reason. If you decide not to participate, you may still take part in other CDC programs and research, now or in the future, without forfeiting benefits. You may also withdraw from this study without penalty after starting your interview. Even if you agree to participate, you are not required to answer all the questions you are asked. As part of a dyad, we ask that you keep the information discussed today confidential.

### COMPENSATION

You will receive \$20 for completing and participating in the interview.

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## QUESTIONS

Do you have any questions?

You may phone Study Co-Director Dana Brimmer, Ph.D., a contractor with Synergy America Inc., at (xxx) xxx-xxxx to have your questions answered. If you have any questions about your rights as an interview participant, you may call the CDC Human Research Protection Office at (800) 584-8814. Please mention that you are calling in reference to CDC protocol #7057. You may also call the CDC Principal Investigator, Sally Lin, Ph.D., at (404) 639-1646. Calls to Dr. Brimmer or Dr. Lin may be toll calls.

### Participant A:

Given the information that I have just reviewed with you, do you still wish to participate in this study/interview?

If No, \_\_\_\_\_ [*Interviewer's initials*]. That is fine. We appreciate your time. Thank you.

If Yes, \_\_\_\_\_ [*Interviewer's initials*]. Great.

### Participant B:

Given the information that I have just reviewed with you, do you still wish to participate in this study/interview?

If No, \_\_\_\_\_ [*Interviewer's initials*]. That is fine. We appreciate your time. Thank you.

If Yes, \_\_\_\_\_ [*Interviewer's initials*]. Great.

Let's get started. I want to let you know that there are no right or wrong answers for this interview. We'd like you to be honest in your responses.

[Type here]

## Diagnosis and Management (10 minutes)

### **ME/CFS**

1. What is the first thing that comes to your mind when you think of patients with ME/CFS?

**Probe: why those items came to mind if it's not obvious**

- Challenging
- Lack of time
- Difficult patients
- Frustrating

2. Do you think your opinions are typical?

**Probe:** Do your colleagues have different opinions?

3. What information would you gather in order to diagnose a patient with ME/CFS?

**Probe:**

- Medical history
- Assess symptoms
- Diagnostic tests
- Refer to specialists

4. Once a ME/CFS diagnosis is made, what additional information might you seek to guide treatment?

**Probe:**

- Diagnostic tools (or guideline)
- CME courses
- Fact sheets

5. What can be done to improve patient outcomes for patients with ME/CFS?

**Probe:**

- Strategies for treatment/management
- Strategies for communication

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6. Where would you go to find out more information about ME/CFS?

**Probe:**

- Workplace
- CME
- Medical library
- CDC website
- Internet (examples?)

**ME/CFS Patient Scenarios (5 minutes)**

Now I am going to share two scenarios that ME/CFS patients could experience.

**Scenario A**

A new patient says this to you:

“I’ve been to so many doctors who don’t care if I come back or not, because I took up too much of their time. And after so many visits, I’m still as sick as I was at the first time I walked into the door. And when they don’t see results, they are pretty much done But I would like a doctor to just be compassionate and really say “what can I do for you?”

**Questions:**

7. What is the first thing that comes in mind when you hear a patient say something like this?

8. What would you do for this patient?

**Scenario B**

You over hear two people talking in a coffee shop:

“I want a doctor who’s willing to not blame the patient for a disease that seems very difficult to treat, and maybe impossible to cure. . . I find that for patients like me, we don’t necessarily mind too much if the doctor can’t help us. But we mind very much if the doctor blames us, or if a doctor dismisses

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us. But I find if the doctor will be willing to hang in there with the patient that means everything.”

9. What are the barriers/facilitators to hanging in there with a patient?

### Patient Centered Outcomes (15 minutes)

#### **Questions:**

10. What are your goals when managing patients with chronic illnesses more broadly, such as . . . . . ?

#### **Probe:**

- Quality of life
- Symptom management
- Refer to a specialist
- Other

11. Would you manage a ME/CFS patient the same way?

**Probe:** Why or why not?

12. What do you think when you hear the concept “patient centered outcomes”?

#### **Probe: Read definition after hearing answers**

- Quality of life
- Care through patient’s eyes
- Benefits/harms of medical recommendations
- Patient preferences/goals
- Communication

13. What is the best way for healthcare providers to incorporate patient centered outcomes into office visits?

14. What resources do healthcare providers need to incorporate “patient centered outcomes” into clinical practice?

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15. People with ME/CFS may experience the following symptoms:

- fatigue
- post-exertional malaise
- limited function
- sleep problems
- cognitive impairment
- pain

16. What would be helpful to healthcare providers in managing patients with these symptoms?

17. What would prevent you from managing a patient's ME/CFS?

**Probe:**

- Time commitment
- Too expensive
- Too labor intensive
- Complaints from staff
- Hearsay from a colleague
- Others

## Conclusion

That's the end of the formal questions I have for you. Do you have any questions for me? Thank you for your time and participation today.